

Northeast Advocates Together (NEAT) and the New England Directors

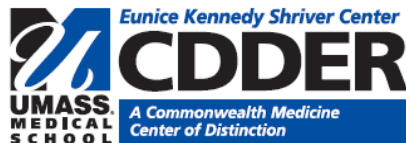


Regional Meeting to Promote

Self Advocacy

In Public DD Systems

Sponsored by



January 26, 2006
Marlborough, MA

DIALOGUE

Self Advocates representing the **Northeast Region of SABE** met with the **leadership of the state DD agencies** from New England and New York to begin an open and positive dialogue about important issues that affect public policy and the service systems that provide support to persons with developmental disabilities in the Northeast United States.



The dialogue was led by **Chester Finn** (President of Self Advocates Becoming Empowered – SABE – and Special Assistant to the NYS Commissioner of OMRDD) and **Theresa Wood** (Director of the VT Department of Aging and Independent Living - DAIL).

National Leadership

This collaboration - across 7 states - represented the first time such a group of leaders joined together to share ideas and begin a planning process to address common issues and concerns on a multi-state regional basis.



“I’ve long admired from afar the ability of the New England states to learn from one another.... (it) can serve as a role model for other states”

Robert Gettings

PARTICIPANTS

Included 47 people from 7 states and the
Executive Director of the NASDDDS, Robert Gettings

| | |
|---|---|
| Connecticut Beth McArthur Jean Bowen Carol Grabbe Kathryn duPree Chad Sinarian Peter O'Meara | New York Chester Finn Kelly Schusch Clint Perrin Neil Mitchell Gary Lind |
| Maine Bill Hughes Jane Gallivan David Goddu Julie Moulton Gayna Cook Maryann Preble James Oldenburg | Rhode Island Bill Guy Maya Colantuono Deb Kney Stephanie Horridge Dianne Ross Sue Babin Kevin McHale |
| Massachusetts Anne Fracht Gerry Morrissey Ed Bielecki Janet George Gail Grossman Tom Fulginiti | Vermont Brenda Ritchie Karen Topper Mike Comstock Dawn Arsenault Kathy Kretz Donna Bennett Ryan Whipple Ellen Malone Theresa Wood |
| New Hampshire Gordon DuBois Roberta Gallant Janet Hunt Tammy Mills | NASDDDS Bob Gettings |
| | UMASS Medical School Alixé Bonardi Steve Staugaitis |

Historic Meeting

“I don’t know anywhere else where...an entire region of the country has come together with the leadership of state agencies and the leadership of self advocacy - to share... and learn from one another.”

Robert Gettings



Maine delegation



New Hampshire delegation



Connecticut delegation

Listening



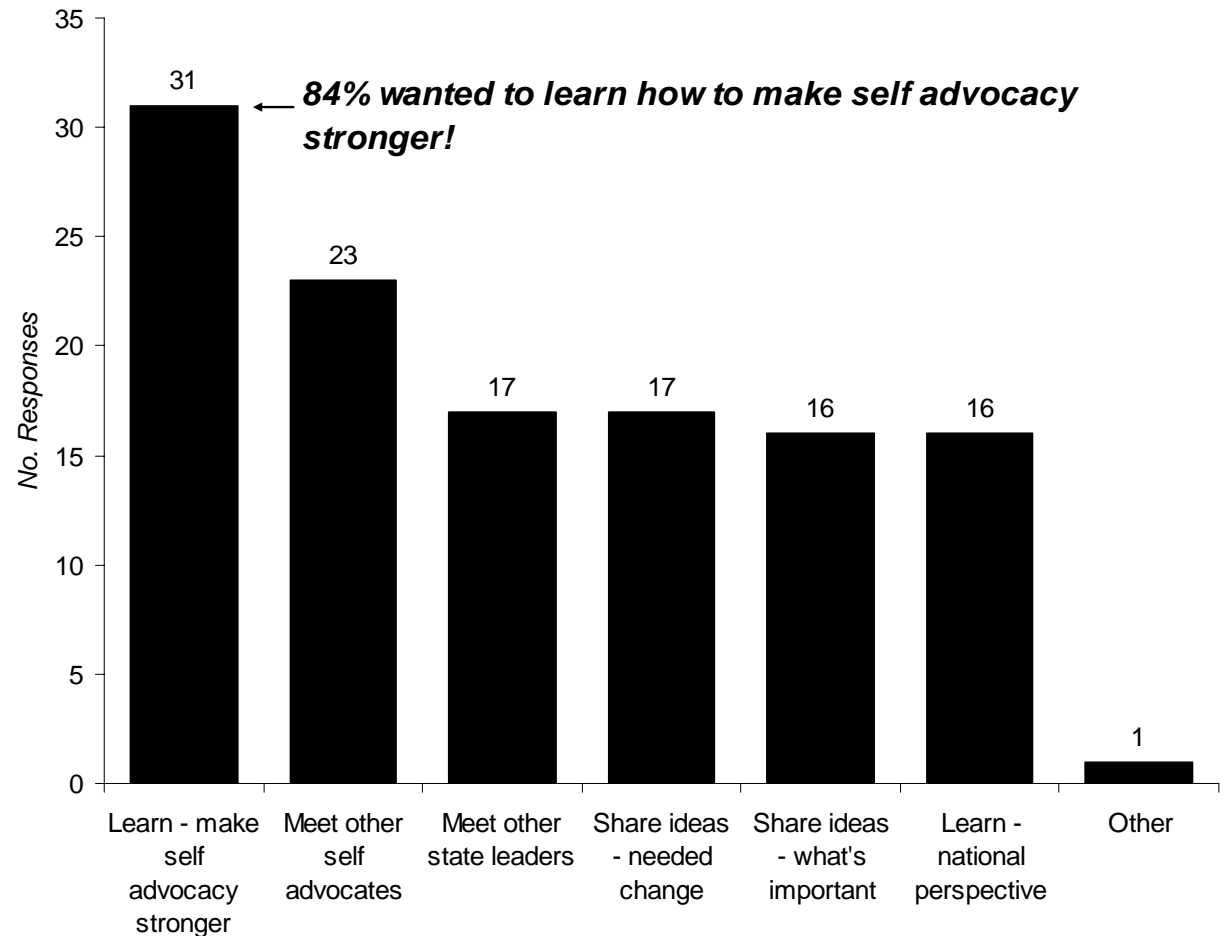
The meeting presented a unique opportunity to spend some time in conversation – sharing ideas and concerns – but most of all, really listening to different points of view and learning about what others are doing to promote self advocacy in different areas of the Northeast.

“Today is going to be about listening to each other.”

Chester Finn

Meeting Goals

A survey helped to identify what people wanted to achieve from the meeting.



What is Self Advocacy?

The meeting began with an introduction and overview provided by Chester Finn. Chester shared a set of principles and values that reflect the foundation of self advocacy and support the need for self advocates to play a major role in shaping public disability policy.



“It comes down to one point, the point of people’s lives – where you live, what you do – your civil rights as well as being a human being and being a part of society – and everyday life.”

Chester Finn

KEY



Carol led an “ice breaker” exercise that allowed meeting participants to answer 20 Questions to arrive at the key word: “Key.”



“It’s a simple word with many different meanings. From a self advocates perspective, if we work together as a team, that’s the KEY to getting things done.”



Carol Grabbe

A thin black outline map of the state of Rhode Island is positioned in the background, centered behind the text. The map shows the state's irregular coastline and its division into five counties.

STATE REPORTS

on Issues and Initiatives
related to Self Advocacy

from the perspectives of
Self Advocates

AND

State Agency Directors



CONNECTICUT

Self Advocacy Issues and Initiatives

- People First has 14 Chapters
- Self advocates: change the DMR name
- Want real jobs with fair pay
- Involved in legislative advocacy
- 9 self advocates are employed by DMR
- Self Advocacy Institute
- Speakers Bureau
- Self Advocates Council
- Involved in hiring and training staff





MAINE

Self Advocacy Issues and Initiatives

- Person Centered Planning - “Hang My Hat”
- Project Independence Plus & the Muskie Center
- Positive working relationship
- Focus on self directed supports
- Connecting self advocates with regional management
- Self directed waiver & creative approaches to guardianship

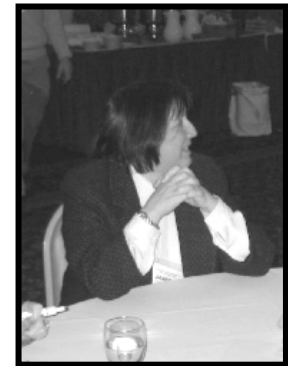


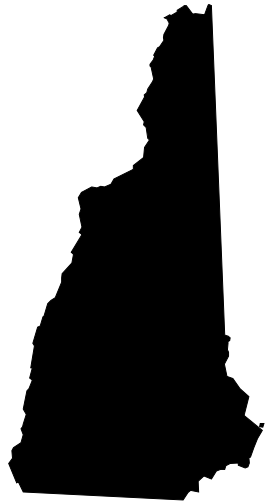


MASSACHUSETTS

Self Advocacy Issues and Initiatives

- 1800 members in MASS
- Handbook and training programs
- More community living and self determination needed
- DMR provides funds to support self advocacy
- Self advocates on Quality Councils
- Paradigm shift toward self directed supports
- Transportation and Employment need improvement





NEW HAMPSHIRE

Self Advocacy Issues and Initiatives

- 14 chapters in People First of NH
- Name change – reviewing regulations
- “Making Your Case” training
- State provides funds for self advocacy
- All Area Agencies have self advocates on their governing/advisory boards
- Regular meetings with the Director
- Active involvement in waiver development





NEW YORK

Self Advocacy Issues and Initiatives

- Self advocates providing training & education re: options
- Annual retreat – helping shape future vision
- Welcoming Communities project
- Paid internship for self advocate leaders
- Participation in agency leadership meetings





RHODE ISLAND

Self Advocacy Issues and Initiatives



- 414 people attended self advocate conference
- March statewide conference will focus on closing Sheltered Workshops
- Curriculum to help self advocates answer Summit questions
- Facing difficult budget year





VERMONT

Self Advocacy Issues and Initiatives

- Video: “Our Bill of Rights”
- 6 Self Advocate Workshops – 2 sessions on “highly effective people”
- Focus: including people on boards
- Toolkit on alternatives to guardianship
- Planning conference on sexuality
- Helped shape Governor’s budget
- Self Advocates: interview for hiring and on Quality Management Teams



3 BIG Issues

formed the foundation for dialogue and
problem solving



Agency Name Change
Sheltered Workshops
Transportation



OR
Real Respect
Real Work
**Real Participation in our
communities**



Close Workshops

Creating opportunities for meaningful work, with decent wages and benefits was a major issue that everyone agreed should be promoted within the state DD systems.



“Getting a job will get you more friends. That is how we all meet our friends”

Clint Perrin

Respectful Language

Self advocates were insistent on the need to use “people first” language and eliminate the use of demeaning labels and words. They were particularly concerned about the use of the term “mental retardation,” especially when included as part of the name for state agencies that support people with developmental disabilities.



“Get rid of labels. It removes dignity and respect and underestimates people’s capabilities...”

Chad Sinarian

Work Groups

Meeting participants formed a series of work groups that included individuals from different states. Each group was responsible for choosing one of the three “Big Issues” and identifying possible solutions. The work groups then reported back to the large group on their “3 Best Ideas.”

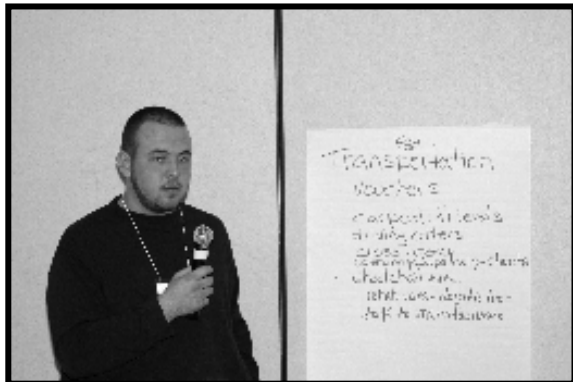


3 KEY IDEAS TRANSPORTATION

✓ Vouchers

✓ Carpooling

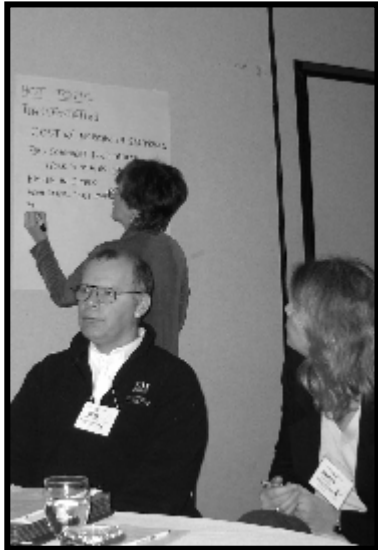
- friends
- cross-agency
- community groups
- churches



✓ Wheelchair Vans

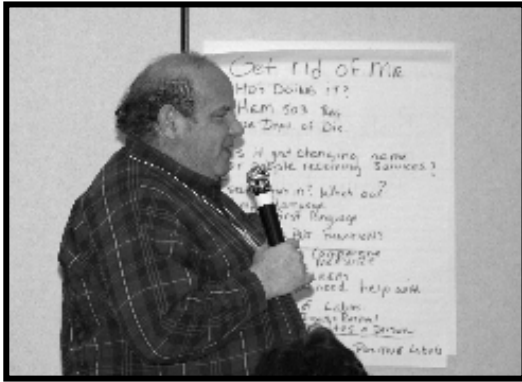
- rehab vans (donations)
- talk to manufacturers

3 KEY IDEAS TRANSPORTATION



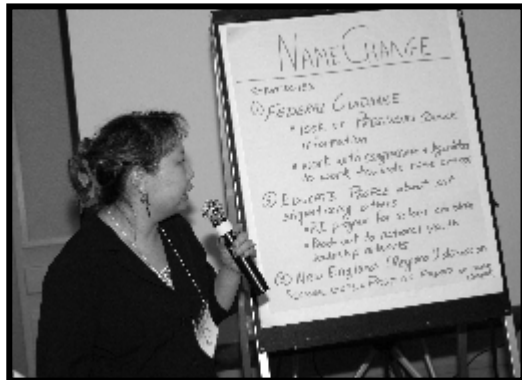
- ✓ **Local advocacy** – change transit routes and schedules
- ✓ **Talk to officials** - invite officials to self advocacy meetings
- ✓ **Knowledgeable staff** - make sure staff are aware of ALL transportation options

3 KEY IDEAS NAME CHANGE



- ✓ **Change Policy:** Use People First Language
- ✓ **Get rid of the “MR” word**
- ✓ **Focus on Functions, NOT Labels**

3 KEY IDEAS NAME CHANGE



- ✓ **Federal Guidance:** lobby and educate government leaders
- ✓ **Educate public** about NOT stigmatizing people
- ✓ **Develop a NE Regional Position Paper**

3 KEY IDEAS

SHELTERED WORKSHOPS



- ✓ **Stop Funding:** no more funding for SW – use individual budgets
- ✓ **Get Parents on board:** educate H.S. parents
- ✓ **Provide T.A.:** Benefits
Counselors, School Transition, help providers re-invent themselves

3 KEY IDEAS

SHELTERED WORKSHOPS



- ✓ **Stop Funding new people in SW's**
- ✓ **Support People:** use person-centered planning, job mentoring, speaker's bureaus
- ✓ **Share Success Stories**

STRENGTHEN OUR RELATIONSHIP

Before adjourning for the day, self advocates and state leaders from all 7 Northeast states agreed it was important to work together and strengthen the relationships both within states and across the region.

“We need to work and nurture and really have both sides equal partners”

Clint Perrin



NEXT STEPS

Agreement for

More Collaboration

Meet Again

Keep Communication Open

Share Information



The New England MRDD Directors Consortium is a formal collaboration that is designed to promote multi-state regional information and resource sharing by state developmental disability agencies. It is coordinated by the UMASS Medical School's Center for Developmental Disabilities Evaluation and Research and is partially funded through a CMS Quality Improvement Grant.

For more information contact:

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Photographs in this presentation are provided through the courtesy of:

Deb Kney, Rhode Island Advocates in Action
Steve Staugaitis, UMASS Medical School

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